

confirms that the dementia of the patient involved is not treatable, the patient's family should have access to surrogate decision making mechanisms that will minimize financial hardship and emotional stress. Unfortunately, such mechanisms currently do not exist.

Legal Issue #2: Indigent dementia patients lacking family or other primary caregivers need conservatorship services but rarely receive them.

California law provides for a county office of public guardian. Each county is responsible for establishing and financing public guardian operations and, as would be expected, policies vary from county to county regarding who is eligible to receive services. Private agencies may be bonded to provide conservatorship services but, because compensation is not available, private agencies rarely serve indigents. Public guardians also sometimes refuse to serve indigents, arguing that no estate exists to be managed.

The uncertain availability of conservatorship services poses obvious problems for indigent dementia patients. Such patients lack the capacity to make competent decisions regarding their own health care but, nevertheless, can refuse care. Lacking conservators, these patients are allowed to suffer the consequences of their own incompetent decisions.

Legal Issue #3: California law does not identify the order in which family members may, in the absence of other legal steps, assume decision making power on behalf of dementia patients.

When a dementia patient is not able to give informed consent, has not executed a durable power of attorney for health care (DPAHC), and is not a conservatee, it is not clear under current California law who may make health care decisions on the patient's behalf. Only 5-12 percent of dementia patients are estimated to have executed durable powers of attorney for health care. In most cases, the selection of the surrogate decision maker remains a relatively informal process. Typically, one or more family members assume the responsibility and follow a consensus approach to health care decision making. Where there is disagreement, there is no formal mechanism for breaking the deadlock, and physicians may simply refuse to act for fear a dissenting family member may take legal action.

Other states have family-succession laws providing clear legal authority for family members to make health care decisions and identifying the order in which family members may, in the absence of other legal steps, assume decision making power. Some states' laws include criteria for determining under which circumstances this may be undertaken, as well as by whom, and when family succession should be superseded by other legal interventions, such as durable power of attorney or conservatorship. The Model Health Care Consent Act (9 Uniform Laws Ann. 332 [West Supp. 1984]) gives equal priority to all family members and provides no guidance on procedures where there is disagreement.

California law is not without precedent. Patients in nursing homes are afforded the right to be fully informed of their medical condition, unless medically contraindicated, and to refuse treatment to the extent permitted by law (22 CA. Admin. Code Section 72527 [a][3][4]). These rights devolve to the "patient's guardian, next of kin, sponsoring agency or representative payee" if the patient is not able to give informed consent (22 CA. Admin. Code Section 72527 [c]).

Legal Issue #4: Current California law allows division of community property into equal shares of separate property for the purpose of obtaining, under Medi-Cal eligibility rules, skilled nursing or intermediate care for a spouse afflicted with dementia. Such division of property is not allowed, however, to obtain for in-home or community-based care covered by Medi-Cal.

Current law allows division of community property--that is, making half of all of a married couple's community property the separate property of each spouse. In addition, the family home may be transferred from one spouse to the other as a gift. Division of assets has ramifications in the realm of Medi-Cal eligibility. Specifically, if a written agreement has been executed, Medi-Cal will base eligibility for skilled nursing facility reimbursement on each spouse's separate property. In other words, one property share will be "spent down" to pay for one spouse's care in a skilled nursing or intermediate care facility (SNF/ICF) without jeopardizing the other spouse's resources or Medi-Cal eligibility at a later date.

If no written property settlement was previously executed, Medi-Cal will allow a division of community property assets to be executed as of one spouse's first day of placement in a SNF or ICF. This is referred to as an "automatic" division of community property and does not allow the gift of the family home. Should the institutionalized spouse return home, this automatic division is cancelled.

Because Medi-Cal rules currently do not acknowledge division of assets except to pay for care in a skilled nursing or intermediate care facility, current law encourages unnecessary placement of dementia patients in these facilities because resources are not available to pay for lower levels of care. Dementia patients require care over a very long time. Much of this care is, or could be, provided in the home by family caregivers when respite care and other community-based programs are available to prevent the entire caregiving burden from falling on families. Current state law pertaining to division of community property forces the full burden of this long-term cost to fall on the dementia patient's spouse until the patient is institutionalized.

Recommendations

A. The Governor and Legislature should amend current California law to provide for an "Irreversible Dementia Conservatorship" (IDC) to include but not be limited to the following powers:

1. To authorize, without court approval, involuntary medical and health care treatment for an Alzheimer's disease or related dementia patient, including mental health treatment, as an inpatient in acute care or long-term care facilities or on an outpatient basis;
2. To authorize involuntary placement of an Alzheimer's disease or related dementia patient in a locked facility or a secure environment; and
3. To manage an Alzheimer's disease or related dementia patient's financial decisions and/or his or her estate.

Such conservatorship shall be court-appointed and require the series of diagnostic tests necessary to enable an attending physician to ascertain whether a given patient's dementia is due to treatable causes and is therefore potentially reversible.

B. The Governor and Legislature should identify alternative mechanisms by which the request of a family member, health professional, or long-term care ombudsman would trigger review of the medical declaration that reversible causes of dementia had been ruled out with respect to any individual patient placed in a locked facility or secure environment or any patient on conservatorship.

C. The Governor and Legislature should amend State law to require county offices of the public guardian to provide conservatorship services for indigent dementia patients. The State should reimburse counties for the cost of providing these services under the terms of current law pertaining to State mandated local programs. Finally, the health insurance surcharge recommended in the "Finance" section of this report should be considered as an appropriate source of funds to pay the cost of providing conservatorship services to indigent dementia patients.

D. The Governor and Legislature should amend current law to specify the order in which family members may assume decision making power on behalf of dementia patients. The following order of succession is that found in Probate Code Section 1812:

1. Spouse;
2. Adult child (in order of age);
3. Parent;
4. Brother or sister (in order of age);
5. Grandchild (in order of age, if over 18);
6. Any other interested person.

E. The Governor and the Legislature should eliminate the legal barriers to allowing division of assets for purposes of enabling Alzheimer's disease and related dementia patients to become eligible to receive in-home and community-based services as alternatives to institutionalization.

F. The Governor and Legislature should amend State law to require the Department of Aging to specify that annual services plans prepared by Area Agencies on Aging and submitted to the department for approval and funding shall include provisions for dissemination of information on the legal rights and opportunities to qualify for care and services appropriate to Alzheimer's disease and related dementia patients and their families. Furthermore, the Departments of Aging, Health Services, and Mental Health should publish information on legal rights and availability of services and disseminate these materials to all California physicians, psychologists, licensed clinical social workers, marriage and family therapists, adult day care and adult day health care centers, community mental health centers, and all other programs serving the needs of Alzheimer's disease and related dementia patients.

V. TRAINING AND EDUCATION

Training and education are related to each of the sections in this report. They recur as themes whenever care, finance, legal, or research issues are discussed in the context of Alzheimer's disease and related dementias. Care providers, whether they are professionals, family members, para-professionals, nursing staff, or volunteers, must be both encouraged and given the opportunity to obtain the best of training that can be made available to them. Those providing financial or legal advice or services to dementia patients and their families need to be aware of the numerous subtleties that affect decision making by and for these individuals. New researchers must continue to receive training so that they can bring state-of-the-art approaches based on sound scientific principles to bear on the problems of Alzheimer's disease and related dementias.

Families of dementia patients, even those not intimately involved in direct patient care, need to be educated about the needs of the patient and primary caregiver alike, in order to provide each other with the support necessary to withstand the stresses of caregiving and to make sensible and thoughtful decisions regarding how to meet caregiver and patient needs. The public, chief provider of a large portion of the resources committed to caring for those afflicted with Alzheimer's disease and related dementias, should be provided information about public and private ramifications and implications of the long-term care needs and costs associated with these tragic disorders.

Training and Education Issue #1: Current training and education for medical and allied health professionals stresses acute care and provides only limited opportunities for students to gain experience in treating patients with chronic conditions, especially those in long-term care facilities.

Professionals who do not feel competent to manage dementia tend to avoid those patients. Where they must provide care despite their lack of training, that care is likely to be of lower quality. Multidisciplinary training in dementia care is rarely included in the curriculum of schools for health professionals, including doctors, dentists, nurses, pharmacists, and social workers.

Professionals dealing with dementia patients should be understanding of and sensitive to the needs of patients and their families. More students may be encouraged to specialize in dementing diseases as they become more aware of the needs for research and the enormity of the problem of providing care for dementia patients. Currently, education stresses acute rather than chronic care

and does not provide adequate experience and information about the long-term care requirements of dementia patients. The lack of interest among medical professionals in working with dementia patients may stem from this inadequacy in training and education. Although more opportunities are necessary, some professionals in California have the opportunity to work with dementia patients at Alzheimer's Disease Diagnostic and Treatment Centers and other medical facilities.

A few California medical and nursing schools now require their students to participate in nursing home rotations, thereby giving these students an opportunity to learn first-hand about geriatric and dementia patients. When made a permanent fixture in professional health care education, these programs help to focus trainee attention on quality in long-term care. Rotating students through a nursing-home environment is not typically included in the curriculum for medical, nursing, social work, psychology, or law students in California's state college and university system, or for that matter, in independent or community college systems.

Very little staff development directed towards the care of dementia patients is offered in long-term care settings. Where it is offered, it is usually because of the personal commitment of an administrator, nursing director, or other person in a position to implement it. Additional specially designated funding would enable skilled nursing facilities to create positions for interns in their facilities. Currently, nursing homes that provide such teaching opportunities are rare. On-site training has proven generally more effective than training situations that require staff travel to outside training sites or attendance at classes during non-work hours.

Training and Education Issue #2: Training resources are particularly scarce in rural areas.

Model diagnostic and treatment centers for dementia in California are generally centered in urban areas and are usually located in medical schools which are inaccessible to many practicing professionals and service providers. Due to geographic remoteness, rural areas experience the greatest lack of state-of-the-art diagnostic technology and treatment for dementia patients. Moreover, rural areas attract fewer recently trained health-care workers and fewer still who have received dementia or geriatric training. Although rural areas have developed caring, informal support networks and have attracted dedicated medical professionals, the severe behavioral management problems seen in many dementia patients require specialized expertise. This expertise is rarely available outside of urban centers.

There are precedents for providing enhanced services in rural settings. The Department of Mental Health's Short-Doyle program funds geriatric mobile assessment teams. Also, field services specialists for children are sent to local public health departments by the Department of Health Services' California Children's Services program. Such mobile staff and facilities not only provide specialized diagnostic services in rural settings, but they also serve as temporary training centers for caregivers, medical professionals, and other service providers. Mobile units offer continuing education and training in the latest service-delivery and patient-management techniques.

The clinical assistance and supervision provided by mobile trainers enables local practitioners to receive feedback and technical assistance on difficult cases and helps to ensure the development of practical skills. In addition, making peer consultation available in rural areas helps to overcome one of the objections professionals have to working in rural settings. In areas where few professionally trained health-care providers practice and offer their services, mobile training units enhance the quality of care available to dementia patients by providing training for professionals such as public health nurses, who are not normally considered part of an Alzheimer's disease care system. Unfortunately, resources have not been available for establishing an Alzheimer's disease program in underserved areas.

Training and Education Issue #3: Inadequate training for family caregivers can result in inadequate care for dementia patients or, at worst, abuse.

Abuse or neglect of dementia patients frequently arises from a caregiver's not knowing how to manage difficult patient behaviors. Family caregivers, other family members, and society in general are poorly informed both about dementia and about appropriate care for dementia patients. Poor dissemination of educational material directed specifically to dementia patients and their families serves as a barrier to obtaining appropriate services. Caregivers need to become familiar with the practical, at-home management of dementia patients' difficult behaviors. They need to know what are considered ethically and legally acceptable methods of behavior control. They need training in how to identify and deal with their own emotional and support needs.

Education on dementia-related legal issues is virtually non-existent. Provider and consumer education, with specific emphasis on advanced planning for the later stages of the disease, could help families and professional caregivers cope rationally with the array of issues which confront them. Typically, families turn to medical professionals, attorneys, and the clergy for advice but they frequently discover that these professionals are unsure which medical, legal, or moral principles apply in the case of dementia patients.

Training and Education Issue #4: The public is poorly informed of the financial demands families may face in providing long-term care for a dementia patient as well as the limitations on long-term care coverage available under Medicare and Medi-Cal.

The public is poorly informed about the potential financial problems related to caring for a dementia patient. This unfortunate condition is primarily attributable to the fact that a majority of the elderly, much less the general population, do not know the limitations on long-term care coverage available from Medicare, Medi-Cal and private financing mechanisms. This situation can be partially addressed through the provision of financial counseling and educational materials available to dementia patients and their families. A major source of financial counseling in California is that provided by the Regional Resource Centers under the direction of the Statewide Resources Consultant in the Department of Mental Health. The Regional Resource Centers provide professional counseling to brain-impaired adults and their families regarding their financial options and plans. There are currently seven regional centers in the State, with four more necessary to provide State-wide coverage.

In addition, the California Department of Aging sponsors Health Insurance Counseling and Advocacy Program (HICAP) agencies that train and supervise volunteer counselors who provide financial counseling and education services in various settings. Currently, there are 10 HICAP agencies serving a total of 27 counties. These services are not available in all 33 of Aging's planning and service areas throughout the State and, where available, the agencies only provide minimal services to dementia patients and their families.

Recommendations

A. The Governor and Legislature should direct California's medical, dental, law, social work, nursing, psychology, gerontology and related professional schools to include dementia and long-term care curriculum offerings and rotations. In addition, funding should be available to these schools for the development of geriatric and dementia curriculum materials and to give schools and long-term care facilities incentives to participate in a concerted effort to upgrade professional and para-professional training and education with specific reference to dementia.

B. The Governor and Legislature should make a provision for the development, staffing, and funding of mobile diagnostic, treatment, and training units to serve dementia patients and their caregivers in rural and other underserved areas. These mobile units also will provide continuing clinical education in diagnostic techniques and treatment interventions for those health-care professionals who are working in underserved areas and who lack other opportunities to receive such training.

C. The Governor and Legislature should create a specialized training program in dementia and long-term care issues for volunteer care providers in order to encourage the involvement of volunteers in assisting dementia patients and their families.

D. The Secretary of Health and Welfare should direct the Departments of Aging, Health Services, Mental Health, and Social Services to expand their efforts to disseminate personal, legal, financial, and social services information on Alzheimer's disease and related dementias to the public, physicians, attorneys, programs for seniors, and long-term care providers. Specifically, the Governor and Legislature should direct the Department of Mental Health to expand the provision of financial counseling and information on Medicare, Medi-Cal, and private insurance coverage of community-based and institutional services to families of brain-impaired adults through the Regional Resource Centers. In addition, the California Department of Aging should ensure that financial counseling and information dissemination specifically for dementia patients and their families be provided through the HICAP program and by all 33 Area Agencies on Aging.

E. The Secretary of Health and Welfare should implement a 24-hour telephone information service for families and caregivers for information regarding services and programs addressing the needs of dementia patients and their caregivers.

F. The Department of Health Services should collaborate with the federal Alzheimer's disease research clearinghouse efforts to collect and disseminate information regarding Alzheimer's disease research.

VI. RESEARCH

The causes of Alzheimer's disease and many of the related dementias remain unknown. While biomedical researchers are seeking causes, cures, preventions and treatments, caring for dementia patients costs Californians billions of dollars per year and the costs are escalating rapidly. Possible causes of Alzheimer's disease include abnormalities in the production or metabolism of chemical messengers within the brain (neurotransmitters), toxic metals (e.g., aluminum), pollutants, abnormalities of chromosomes and genes, changes in the immune system, transmissible agents, and many more. None has been firmly established. There is strong evidence, for example, that hereditary factors are important in many families with Alzheimer's disease and that abnormal DNA in chromosome 21 may play a part. Many more families, however, need to be studied and observed for extended periods of time before questions concerning causes of Alzheimer's disease can be answered. Consequently, most current basic research is devoted to investigations of possible causes and means of early diagnosis. There is as yet no cure for Alzheimer's disease, and the progressive deterioration it causes remains irreversible. This is also true for related dementias such as Parkinson's, Pick's, Creutzfeldt-Jakob, multi-infarct, and AIDS dementia.

There is at present no specific diagnostic test for Alzheimer's disease. Neither blood, urine, spinal fluid, nor x-ray reveals the presence of Alzheimer's disease. Such diagnostic tests are urgently needed, and investigators are pursuing various leads. The only currently accepted definitive proof, other than brain biopsy, is autopsy evidence of the classic brain lesions (areas of abnormality): plaques, tangles, and cerebral vessel amyloid. As previously stated, misdiagnosis is a tragedy for patient and family alike as well as extremely costly to the State when it leads to long-term care of a person who could have been treated successfully if the correct diagnosis had been made.

Health services research is concerned with the applications of basic biomedical research to improve the quality, appropriateness, and delivery of health care. It encompasses the multidisciplinary study of patients with dementia and of the systems that provide patient care. Health services research related to Alzheimer's disease most frequently involves data gathering and analysis in epidemiology, patient assessment, service needs, availability of and access to services, cost of care, quality assurance, and measurement of outcomes.

Research in California

The State of California directly funds Alzheimer's disease research through the Alzheimer's Disease Program in the Department of Health Services. Funding currently is set at only \$750,000 for 1987 and will remain the same for 1988. Biomedical research in the State of California has been directly responsible for many of the recent advances in our knowledge of Alzheimer's disease and related dementias as well as in diagnostic technology.

Two of the ten Alzheimer's Disease Research Centers in the United States established by the National Institute on Aging are located in California and the State of California maintains six Alzheimer's Disease Diagnostic and Treatment Centers, administered by the Department of Health Services. All centers are located in university settings where basic and clinical research can be combined. State funding for the Alzheimer's Disease Diagnostic and Treatment Centers currently provides for an average annual budget of \$115,000 at each site; this amount will increase to \$250,000 in FY 1987-88. Yet there exist other public and private California university medical centers pursuing basic and clinical research programs in Alzheimer's disease and related dementias without any State funding. The unfunded institutions, as well as existing programs, urgently need State support.

California as an Ideal Site for Alzheimer's Disease Research

The high number of elderly in California, the State's ethnic diversity, as well as its renowned universities, make California ideal as a site for research into risk factors, causes, and treatment of Alzheimer's disease and related dementias, as well as cultural and environmental differences in the nature and course of the disease. The largest number of Alzheimer's disease patients in any state--and the largest number of caregivers--live in California. The cost of providing long-term care for dementia patients represents a significant portion of the public expense for social and health services. Without support of medical research we will never see the end of Alzheimer's disease and thus the elimination of this enormous cost of care.

Current health policy increasingly assigns to states the primary responsibility for long-term care. It is, therefore, in California's interest to invest in the knowledge base needed to effectively treat and prevent Alzheimer's disease and related dementias.

Research Issue #1: The current level of State funding for Alzheimer's disease research is not commensurate with the magnitude of the problem.

The only hope we have to find the cause of and cure for Alzheimer's disease is through basic research. There are an estimated 715,000 individuals in California suffering from Alzheimer's disease and related dementias. The cost of care for Alzheimer's disease, the fourth major cause of death in the United States, may be greater than the cost of care for heart disease, cancer, and stroke (the first three major causes of death) combined; yet, federal funding for Alzheimer's disease research is less than 3.5 percent of the total research funds for the other diseases. State spending for Alzheimer's disease research--at \$750,000 annually--represents only 0.02 percent of the total public and private annual cost of care. Such disproportionately low State spending for dementia research fails to prepare California for meeting the demands of dementia patients whose numbers will increase dramatically over the next several decades as the average age of the general population rises--unless we find the means for prevention and cure.

Research investigations of Alzheimer's disease and related dementias require a broadly based approach due to the complexity of the illness. Such research mandates the involvement of the biomedical and psychosocial sciences in a wide spectrum of research sustained by stable funding from a variety of sources. Private organizations--such as the Alzheimer's Disease and Related Disorders Association (ADRDA) and several foundations--have contributed a total of only \$10 million over the last five years to research projects nationwide. Even though federal funding for dementia research has increased substantially, the combined funds are inadequate to support even the ongoing work. Research is needed into the role in the dementias of such factors as genetics, nutrition, chemicals, infections, trauma, and drugs. This type of research is of vital importance but requires years, if not decades, to yield its results. Meanwhile, patients and families need symptomatic relief, and State agencies need information so they can make meaningful plans for health service delivery. Hence, there is also a need for health services delivery research including data gathering and analysis in epidemiology, patient assessment, service needs, service availability and accessibility, cost of care, quality assurance, and measurement of outcomes. Finally, comprehensive clinical care research programs need to be developed focusing on diagnostic issues and psychopharmacologic, behavioral, social and psychological treatment interventions in rigorously designed clinical trials. Although the latter research areas are of immediate practical value, they depend on the foundation of knowledge provided by basic biomedical research. For example, when state-of-the-art applied research was seeking better iron lungs for polio victims,

more basic biomedical research provided the polio vaccine. A judiciously balanced selection of various types of research efforts is therefore essential. Appropriate levels of annual State funding for such studies could prove to be beneficial by reducing both the incidence of dementing disorders and the costs of caring for dementia patients.

Research Issue #2: The allocation of resources currently available for research often fails to meet the most pressing needs of both the research community and dementia patients themselves.

New researchers frequently have fresh insights into long-standing research problems but are effectively barred from access to funding in the existing decision-making process, which emphasizes experience and reputation over promising methodologies and approaches. Seed money to initiate innovative research by such investigators will subsequently attract much larger amounts of federal funds which will be distributed not only to investigators but also to their institutions. These types of funds increase the financial pool designated for research in California and enhance those areas for which California is unique, e.g., its ethnic diversity. State funds could provide data specific to the informational needs of California as well as develop skilled investigators adding to the State's human resources, particularly in the biology-based and health services sectors which are growth areas for California's high-tech economy.

A related problem has to do with the lack of a source of one-time emergency funding needed to finish an investigation which cannot be completed with the initial funding provided or which began with an "understanding" regarding future funding and faces premature termination due to unanticipated budget cuts. This situation represents a truly unnecessary waste of resources expended in setting up and maintaining a specialized research laboratory as well as assembling a team of qualified investigators.

The nature of Alzheimer's disease, with its extended course (five to 20 years), requires that many research projects concerned with the disease be long-term in order to collect data from the onset of the disease or first diagnosis through autopsy verification of the diagnosis. For example, family data on heritability and health services and epidemiologic research are based on information obtained from patient populations and their caregivers and families over long periods of time. Such data bases are not available for California. Therefore, longitudinal studies addressing Alzheimer's disease and related dementias are required.

Agencies within the State of California currently are not organized in such a way as to make the best possible use of resources available for research investigations of Alzheimer's disease and related dementias. The ability to coordinate resources for research is an essential component of an overall effort to improve quality of care and availability of services for dementia patients.

Research Issue #3: The error rate in the diagnosis of Alzheimer's disease is estimated to be approximately 20 percent.

The initial symptoms of Alzheimer's disease are similar to symptoms of at least 60 other diseases. Because no diagnostic test exists specifically for Alzheimer's disease, a diagnosis is made through a process of clinical evaluation of the patient's history and elimination of other causes of cognitive and memory impairment. This evaluation encompasses a complete medical history and clinical examination, including mental status and routine laboratory tests. When indicated, psychiatric evaluation, neuropsychologic testing, electroencephalograms, and computed tomography (CT) scan or magnetic resonance imaging (MRI) are procured.

The diagnostic process is lengthy and costly, and the error rate in diagnosis throughout the United States may be as high as 20 percent. Patients diagnosed as having Alzheimer's disease sometimes are admitted to skilled nursing facilities without having had complete evaluations to substantiate the diagnosis. An accurate diagnostic process would prevent people from being institutionalized for Alzheimer's disease when they do not have it as well as help families to accept the prospect of having to assume the responsibility of care for the patient when the cause of symptoms indeed turns out to be Alzheimer's disease.

Pending the development of specific diagnostic tests, autopsy confirmation is essential. Since evidence increasingly suggests that Alzheimer's disease may be a systemic disorder affecting many different cells throughout the body, researchers need opportunities to preserve tissue from body sites other than the brain.

Diagnostic errors may have particularly serious consequences when autopsy reveals that a patient with the clinical diagnosis of Alzheimer's disease actually had Creutzfeldt-Jakob disease, a form of rapidly fatal and irreversible dementia due to a transmissible agent. Tissue for transplant purposes is frequently removed and used before the definitive diagnosis is made, and Creutzfeldt-Jakob disease has been transmitted by corneal grafts and by growth hormone isolated from pituitary extracts derived from such patients.

Research Issue #4: Claims are repeatedly made that some remedy or another is effective in curing, arresting, or retarding the progress of Alzheimer's disease or related dementias.

Because currently there is no cure, patients and families are eager to test any claim, eager to try even the most unlikely approach. Confusion surrounds the term "treatment" and the unscrupulous find a ready market. If the term "specific treatment" is restricted to non-experimental, FDA-approved treatments that are curative, preventive, or can arrest the progress of Alzheimer's disease, none qualifies as of today.

Recommendations

A. The Governor and Legislature should immediately implement a program of systematic investment in research on Alzheimer's disease and other dementias as a line item of the State budget. The goal for this annual State dementia research allocation should be one percent (1.0%), but in no event no less than three-tenths of one percent (0.3%), of the total cost of care for dementia patients in California.

B. The Governor and Legislature should develop the mechanism to support a broad spectrum of research on Alzheimer's disease and related dementias. The program should: (1) take into account the multi-ethnic composition of the State of California and its unique physical, geographic and psychosocial setting; (2) include, but not be limited to, family studies; biologic, genetic, and nutritional factors; toxins, chemical pollutants, infections, and drugs; (3) include long-term projects focusing on family studies, health services and epidemiological research; and (4) include clinical care research focusing on diagnosis, psychopharmacologic, behavioral, social, and psychological treatment interventions in rigorously designed clinical trials. The Secretary of Health and Welfare, in consultation with the Alzheimer's Disease Public Advisory Committee, should establish Alzheimer's disease research priorities to guide the allocation of new resources as they become available.

C. The Governor and Legislature should designate the Health and Welfare Agency as the single State agency responsible for coordinating research on Alzheimer's disease and related dementias.

D. The Governor and Legislature should provide limited amounts of non-renewable initial funds to support innovative research projects on Alzheimer's disease and related dementias proposed by individual investigators.

E. The Governor and Legislature should provide emergency or hardship funds to maintain the laboratories and research teams of established outstanding investigators in Alzheimer's disease and related dementias who have experienced substantial reductions in funding.

F. The Secretary of Health and Welfare should develop and implement regulations and disseminate information that no organs, tissues, blood, or other bodily fluids should be accepted for administration to any other human being by whatever route (injection, transfusions, transplantation, etc.) from a patient with dementia or from autopsies of such patients. Specifically, no tissues from autopsies of demented patients should be used for live tissue banks (e.g., corneal or pituitary banks) for transplant or hormone extraction purposes.

G. The Secretary of Health and Welfare should ensure that all medications and other treatments advocated for Alzheimer's disease be identified as to whether they are or are not Food and Drug Administration (FDA) approved, and whether they are or are not experimental. The term "specific treatment" should be restricted to those FDA-approved, non-experimental treatments that are curative, prophylactic, or can arrest the progress of the disease. Treatments affecting symptoms but not the course of the disease are to be identified as "supportive" or "symptomatic" treatments. Treatments of unknown value should be specifically so designated.

VII. PROPOSAL FOR AN ALZHEIMER'S DISEASE PROGRAM

In the case of Alzheimer's disease and related dementias, California's health and social services system is inadequate. The current system of care has not yet evolved to the point of being able to provide services designed to meet the unique care needs of this target population. The ideal health and social services system should be a continuum of care that includes flexible service delivery so as to provide neither more nor less care than is needed.

Dementia patients are usually cared for at home by a spouse or adult child. Because of a lack of community-based services and/or a lack of access to such services, premature institutionalization often occurs. Not only is such institutional placement usually inappropriate, but it wastes increasingly scarce public resources. Also, inadequate in-home and community-based care places the enormous burden of 24-hour care on the caregiver. Thereby the disease usually claims a second victim, the caregiver, who may lose employment, opportunities for social interaction, financial resources, and often his or her own good health.

During the past two years, the Task Force has listened to the people of California who have described the impact of the emotional and financial hardships dementia imposes on patients, families, and caregivers. It has become apparent that dementia patients have particular health and social service needs which are not being met. Systems of care that try to fit dementia patients into existing eligibility and service need categories--rather than trying to modify existing eligibility and service need categories to fit the conditions and circumstances peculiar to dementia patients--cannot but fail.

The State must develop an ongoing, formalized capacity to implement and refine the recommendations in this report and to continue searching for ways to improve California's existing system of health and social services to meet the needs of dementia patients along their own unique continuum of needs for care. All departments responsible for administering such programs must be required to respond to the unique needs of dementia patients and their families. California's system of health and social services can meet these individuals' unique needs for care and support if the State will make an ongoing, well-coordinated effort to make existing service providers aware of and sensitive to the nature of Alzheimer's disease and related dementias.

Recommendations

A. It is recommended that the Governor establish an Alzheimer's Disease Public Advisory Committee (ADPAC) and an Interagency Coordination Team for Alzheimer's Disease (ICTAD) to oversee existing programs and implement the recommendations of this report. California needs a concerted, high-level effort, to enable existing social and health services programs to make the modifications necessary to provide a continuum of care for Californians afflicted with Alzheimer's disease and related dementias. It is further recommended that these two groups be located and function within the Office of the Secretary of the Health and Welfare Agency where most dementia programs are currently located.

- The Alzheimer's Disease Public Advisory Committee is to serve as the mechanism to: (1) provide ongoing guidance to the administration and the Legislature as to the program needs of patients with Alzheimer's disease and related dementias and their families, (2) review, in conjunction with the Interagency Coordination Team for Alzheimer's Disease, the implementation of Alzheimer's disease programs within the State of California, and (3) encourage the collaboration of the public and private sectors in the development of Alzheimer's disease programs. The Alzheimer's Disease Public Advisory Committee is to consist of 20 members encompassing the Alzheimer's Disease Task Force, expanded to include additional family members, caregivers, providers, and community representatives. The Alzheimer's Disease Public Advisory Committee is to meet at least quarterly.
- This Interagency Coordination Team for Alzheimer's Disease is to ensure the implementation of the recommendations of this report in an efficient and timely manner. The Interagency Coordination Team for Alzheimer's Disease is to include, but not be limited to, representatives from the following: Department of Aging; Department of Health Services; Department of Insurance; Department of Mental Health; Department of Social Services; and Office of Statewide Health Planning and Development. In addition, one full-time Alzheimer's Disease Program Coordinator is to be appointed in the Office of the Health and Welfare Secretary.

B. It is recommended that the Secretary of Health and Welfare be prepared to report no later than January 1, 1989, on the progress of implementing Alzheimer's disease programs in California to provide a continuum of care and research specific to the needs of Alzheimer's disease and related dementia patients and their families.

GLOSSARY

ALZHEIMER'S DISEASE - A chronic progressive disorder that is the major cause of degenerative dementia in the U.S. (affecting as many as 3 million people nationally and 715,000 in California). At present, its cause is unknown. The disease manifests itself with clinical symptoms of dementia and characteristic microscopic changes in the brain. Definitive diagnosis can be obtained only from examination of brain tissue. There is no fully effective method of prevention, treatment, or cure.

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION (ADRDA) - A non-governmental organization founded in June 1979 by several family support groups. Focusing on dementia and the needs of caregivers, its activities include public education, family support, patient advocacy and research. The national office is located in Chicago.

ALZHEIMER, ALOIS - (1864-1915) A German physician who studied the relationship of change in the structure of the nervous system to disease, and who first described the behavioral and pathologic changes in the disease that carries his name.

AMYLOID - Fibrillar deposits composed of proteins in vessels and plaques in the brains of Alzheimer's disease patients.

APHASIA - Loss or impairment of the power to use words, including speaking and writing.

APRAXIA - Impairment of the ability to perform complex coordinated movement, such as walking, dressing, eating a meal, or maintaining a sitting position.

AUTOPSY - An examination of the tissues after death to determine its cause and the presence of disease processes.

COGNITIVE ABILITIES - The functions of memory, intelligence, learning ability, calculation, problem solving, judgment, comprehension, recognition, orientation, and attention. Impairment of these functions is a central feature of dementia.

DEMENTIA - Decline in mental function and thought processes from a previously attained intellectual level lasting months to years rather than days to weeks. Dementia can be caused by over 60 reversible and currently irreversible disorders, but the leading cause in the United States is Alzheimer's disease.

FAMILY SURVIVAL PROJECT FOR BRAIN-IMPAIRED ADULTS - A private non-profit program in San Francisco that provides information, advice and referral, case coordination, legal counseling, and support services to brain-damaged individuals and their caregivers.

GENE - The structure in cells containing heritable information of living organisms.

HOSPICE - Service provided either at home or as an inpatient to terminally ill people and their families offering care and support to the family while also enhancing a terminally ill person's quality of life by enabling them to live as comfortably, alertly or independently as possible.

INTERMEDIATE CARE FACILITY (ICF) - Health related services offered in an institutional setting which are less than those offered in a hospital or skilled nursing facility, but more than those offered in residential care.

ORGANIC BRAIN SYNDROME - This term encompasses a variety of dementias, including Alzheimer's disease, multi-infarct (stroke) dementia, Pick's disease, Huntington's disease, and others.

PLAQUES - Collections of amyloid fibrils found outside of nerve cells in the brains of patients with Alzheimer's disease.

RESPITE CARE - The intermittent but continuous provision of services to provide relief to a family or friends who care for an incapacitated person, including those who are cognitively impaired. Respite programs include in-home companion care, in-home personal care, Alzheimer's day care, or short-term stays in a skilled nursing facility, hospital, or residential care facility.

SENILE DEMENTIA - Alzheimer's disease with onset after age 65. Presenile dementia of the Alzheimer's type has onset before the age of 65. Now both are referred to as Alzheimer's disease (AD).

SKILLED NURSING FACILITY (SNF) - Continuous skilled nursing care or other skilled rehabilitative care provided in a residential facility on a 24 hour a day basis.

APPENDIX A

MEMBERS OF THE CALIFORNIA ALZHEIMER'S DISEASE TASK FORCE

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MEMBERS OF THE CALIFORNIA ALZHEIMER'S DISEASE TASK FORCE

Nancy H. Corby, Ph.D., is Director of Psychological Services, Alzheimer's Disease and Memory Disorders Program, Long Beach Community Hospital. She is on the clinical faculty of the School of Medicine, University of Southern California and a research consultant with the Long Beach Department of Public Health.

Loraine Cutler, Ph.D., is the Associate Director for Psychological Services for the University of California, Davis Alzheimer's Disease Diagnostic and Treatment Center. She is an Assistant Clinical Professor of Psychiatry at the UC, Davis Medical School, and is a consultant to facilities and agencies on the care of Alzheimer's disease patients and families.

Joan E. Dashiell, is founder of the Alzheimer's Disease and Related Disorders Association (ADRDA) of Orange County. She is a member of the Executive Board of the National ADRDA. She is former Chair of the California ADRDA Chapter's Public Policy Committee, and currently is a member of the ADRDA Health Services Research Task Force. A member of Ms. Dashiell's family was a victim of Alzheimer's disease.

George G. Glenner, M.D., is Research Professor of Pathology at the University of California, San Diego, School of Medicine. Dr. Glenner is a graduate of the Johns Hopkins School of Medicine and for 26 years was Chief of a research laboratory at the National Institutes of Health in Bethesda, MD. He is internationally known for his research work on amyloidosis and Alzheimer's disease. He is also the Chair, Medical Advisory Board of ADRDA of San Diego, and a former member of the Executive Board as well as the Medical Advisory Board of National ADRDA.

Suzanne H. Harris, is a founder and past President of the Family Survival Project for Brain-Impaired Adults of San Francisco. She is on the board of the Friends of Langley Porter Institute, a member of the Geriatric Coordinating Committee of Community Mental Health, and a representative of the Brain Damage Coalition of California. Her husband suffered severe brain damage following a massive brain hemorrhage.

Thomas Henry, is Administrator of the John Douglas French Center for Alzheimer's Disease. He is experienced in developing special care units for Alzheimer's patients as well as promoting use of geriatric nurse practitioners in skilled nursing facilities.

Lissy F. Jarvik, M.D., Ph.D., is professor of Psychiatry and Chief, Section on Neuropsychogeriatrics, at UCLA, and Chief of the Psychogeriatric Unit at the Veterans Administration Medical Center, West Los Angeles, Brentwood Division. She has been a leader in research on aging and dementia and is co-editor of the new journal, Alzheimer's Disease and Associated Disorders -- An International Journal, the first scientific journal devoted exclusively to Alzheimer's disease.

Josephine A. Juran, M.A., has been involved in the field of gerontological education since 1976 as a "returned" student, and has served as a mental health geriatric outreach worker as well as a family support group and dementia information network leader in the San Bernardino-Riverside area. Her mother passed away recently after a 10-year battle with Alzheimer's disease.

Bob Gene Knight, Ph.D., is Program Manager of Senior Services for the Ventura County Department of Mental Health. He is a fellow at the UCLA/USC Long Term Care Gerontology Center. He has taught at the Andrus Gerontology Center at USC and is the author of Psychotherapy with Older Adults.

David A. Lindeman, D.S.W., is Administrative Director of the Northern California Alzheimer's Disease Center at Herrick Hospital and Health Center (University of California, Davis), and Senior Analyst at the Institute for Health & Aging at the University of California, San Francisco. He is also a Lecturer in Gerontology at the University of California, Berkeley. He has been actively involved in health services research concerning Alzheimer's disease and long-term care, been responsible for administration of dementia services, and developed the Administration on Aging's Alzheimer's Disease Handbook.

Peggy Wallace, Ph.D., is Assistant Professor in the Department of Medical Education at the University of Southern California, School of Medicine. Her primary responsibilities are in the areas of producing and directing instructional videotapes and other media materials, including a 3-part informational videotape series on Alzheimer's disease for caregivers, family members, and health care professionals. Her mother, who suffered from Alzheimer's disease for 15 years, died in 1986.

Consultant:

Zaven S. Khachaturian, Ph.D., is consultant to the Task Force. Dr. Khachaturian is the Director, Office of Alzheimer's Disease Research, and the Associate Director (designate), Neuroscience and Neuropsychology of Aging Program at the National Institutes on Aging, NIH. During a ten year period, Dr. Khachaturian has had the responsibility of developing the Alzheimer's Disease Research Program at NIA, including the Alzheimer's Disease Research Centers, Alzheimer's Disease Patient Registry, and Diagnosis and Epidemiology of Alzheimer's Disease Programs. He has written extensively on Alzheimer's disease and is on the scientific advisory board of several foundations and state task forces.

Former Member:

Rosalie Kane, D.S.W.

APPENDIX B

PUBLIC EVENTS EXPLORING POLICY ISSUES

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PUBLIC EVENTS EXPLORING POLICY ISSUES

EVENT	ATTENDANCE	POLICY ISSUES	PANELISTS
<hr/>			
PUBLIC MEETINGS	309		
Redding San Leandro Fresno Ventura Riverside November 7, 1985		Financing Training Daycare Special Facilities Support Groups	
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RESEARCH SYMPOSIUM			
U.C., Los Angeles December 16, 1985	150	Funding Basic and Applied Research Developing a Process for Expanding Research	John Blass Daniel Maldonado Roberta Blatt William Bondareff Helena Chui Carroll Estes Robert Katzman David Kuhl Asenath La Rue Steven Matsuyama Jerome Yesavage
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CARE SYMPOSIUM			
U.C., San Francisco January 16, 17, 1986	120	Accurate Diagnosis Personal Resources for Caregivers Supportive Services for Patients/Caregivers Upgrading Alzheimer's Disease Services Improve Quality of Care Training/Public Information	Robert Cook-Deegan Joseph Ramsdell Steven Zarit Linda Crossman Ruth Eolkin Jerry Fishman Paul Gould John Hagerty Nancy Orr Diana Petty Jo Ruffin Carol Winograd
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APPENDIX B
(Continued)

EVENT	ATTENDANCE	POLICY ISSUES	PANELISTS
FINANCING SYPOSIUM Sacramento, CA 100 February 20, 1986		Private Insurance Alternatives Expansion of Public Financing Licensure Modifications Disability and Pension Issues Improvement of Cost Data Consumer Education	Jerry Hansen Thomas Jazwiecki Richard Wilcoxon Carole Mindlins Deanna Marquart Sue North Gene Marchi Mary Ann Bailey Nelda McCall Charlene Harrington Roger McNitt Jim Strong Lonnie Mathis Tom Kraus Derrel Kelch Gerald Eggert Paul Papazian
LEGAL SYMPOSIUM U.C., Los Angeles 50 March 6, 1986		Probate Conservatorship for Health Contracted Conservatorship Agencies Protection of Primary Caregiver Legal Standing of Documents Family Succession Law Consumer Education	Michael Gilfix Jonathan Lew Dorthy K. French Joseph Barbaccia Phyllis Gallagher Luann Beberman Maja Jackson Mark Mills Teresa Myers Leslie Rothberg Maria Estrada John Bosshardt Mark Hankin

APPENDIX C

REPORTS TO THE CALIFORNIA ALZHEIMER'S DISEASE TASK FORCE

APPENDIX C

REPORTS TO THE CALIFORNIA ALZHEIMER'S DISEASE TASK FORCE

AUTHORS OF BACKGROUND PAPERS

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Burke Professor of Neurology/Medicine
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DISEASE AND THE STATE OF
CALIFORNIA

DANIEL MALDONADO

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FINANCING RESEARCH: THE
FEDERAL AND STATE
DIMENSIONS

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NANCY MACE
Consultant in Gerontology

CARE OF PATIENTS WITH
DEMENTIA

STEVEN ZARIT

Associate Professor
Andrus Gerontology Center
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THE NEEDS AND PROBLEMS OF
THE CAREGIVER

JERRY HANSEN

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California Department of Health Services

MEDI-CAL COVERAGE FOR
DEMENTIA

GERALD EGGERT

Executive Director
Monroe County Long Term Care Program, Inc.
Rochester, New York

MEDICARE COVERAGE FOR
DEMENTIA: CURRENT
OPPORTUNITIES AND FUTURE
DIRECTIONS

TOM JAZWIECKI

Director
Office of Reimbursements and Financing
American Health Care Association

ALTERNATIVE MECHANISMS FOR
FINANCING THE CARE OF
DEMENTIA

MICHAEL GILFIX

Founder and Director
Senior Adults Legal Assistance
Santa Clara County, California

LEGAL ISSUES AND
ALZHEIMER'S DISEASE

JONATHAN LEW

Staff Counsel
California Department of Aging

THE HEALTH CARE DECISION-
MAKING PROCESS: SELECTED
LEGAL ISSUES

ACKNOWLEDGMENTS

The Task Force would like to express its appreciation to Director Alice Gonzales and the staff of the California Department of Aging. We are particularly grateful to Barbara Alberson, Andree Armstrong, Barbara Fagernas, Ellie Huffman, Bill Ruppert, and Merv Williams, who contributed greatly during the course of Task Force activities. Others whose contributions we would like to recognize are Deanna Marquart (for report writing assistance), Robert Reed, and Luann Beberman.

EDITORS' NOTE

1972-1995
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An additional source of data for this report is the 1987 report of the Office of Technology Assessment (OTA) of the U.S. Congress entitled Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias. This report is quickly becoming the definitive source document for describing various aspects of dementia and the deficiencies in existing knowledge and care systems which result in extraordinary emotional stress and financial hardship for dementia patients and their families. Other major sources are two reports issued recently by the U.S. Senate Special Committee on Aging: Developments in Aging: 1986 (February, 1987) and Financing Care for Patients with Alzheimer's Disease and Related Disorders (November, 1986).